



**Manchester
Metropolitan
University**

Farrar, Bethany (2018) "I Was the Third Parent": A Qualitative Study of Growing Up with a Sibling with Dravet Syndrome. Manchester Metropolitan University. (Unpublished)

Downloaded from: <https://e-space.mmu.ac.uk/621702/>

Publisher: Manchester Metropolitan University

Please cite the published version

<https://e-space.mmu.ac.uk>



“I Was the Third Parent”: A Qualitative Study of Growing Up with a Sibling with Dravet Syndrome.

Bethany Farrar

Supervised by: Dr. Susanne Langer

April 2018

“I Was the Third Parent”: A Qualitative Study of Growing Up with a Sibling with Dravet Syndrome.

ABSTRACT

The impact of child disability on siblings from their own perspective is underrepresented within existing research. In the current body of literature that does exist, research on the effects of rare disorders is in the minority. This qualitative study therefore aimed to investigate the experience of growing up with a sibling with Dravet Syndrome, focusing on long term developments. To allow for this retrospective approach, only adult siblings participated, with ages ranging from eighteen to thirty-six. Semi-structured interviews with six participants produced a comprehensive insight into their journey. A systematic thematic analysis of the data generated three themes: The Challenge of Dravet Syndrome (1), Impact on Family and Daily Life (2), and Impact on Development of Self (3). Although facing periods of adversity, the majority of participants expressed an overall refreshingly positive outlook of their experience. The findings highlighted the need for similar individuals to receive more recognition within society and further long-term evaluation of impacts on siblings through the process of diagnosis and beyond.

KEY WORDS:	DISABILITY	SIBLINGS	REFLECTION	EXPERIENCE	RESILIENCE
-------------------	-------------------	-----------------	-------------------	-------------------	-------------------

Introduction

Dravet Syndrome is a relatively new disorder, first being discovered in 1978 as Severe Myoclonic Epilepsy of Infancy (SMEI) and in 1989 was changed to Dravet Syndrome (Dravet, 2011). The disorder is a rare and complex form of epilepsy with symptoms often emerging within the first year of life and around 70% of cases caused by a de novo mutation of the SCN1A gene (Dravet, 2011). Affecting around 1:15,700 individuals, the condition is on a spectrum characterised with both physical and developmental symptoms (Wu et al., 2015). Symptoms and level of functioning vary with some able to live with only minimal input from others. On the other end of the scale, some require full-time care, perhaps needing more than one carer at any one time whether that be a parent, family member or paid carer. Seizures can be triggered through lights, temperature and screens yet some may occur without trigger, hugely affecting daily life for the individual with Dravet Syndrome as well as the wider family. In addition to the presence of seizures, developmental delays, sleeping difficulties and delayed language and speech are often present (Dominguez, 2017). Many with Dravet Syndrome remain at a developmental age far younger than their biological age with a lot of cases seeing a regression developmentally. They are likely to be on a combination of daily medications to help prevent seizures and control other effects of the disorder as well as having emergency medications which are administered during prolonged seizures.

There is often comorbidity with other conditions such as autism and other learning disabilities. In some instances the disorder is misdiagnosed as conditions such as Lennox Gastaut or a form of Aspergers with epilepsy. Misdiagnosis leads to incorrect medication, therefore failing to subside symptoms. With it being a relatively new developmental disorder, there have been many cases where individuals have not received the correct diagnosis of Dravet Syndrome until later on in life. This can have adverse effects on the individual as well as the wider family as they experience a time of great stress and uncertainty.

Although the disorder is regarded as life limiting for the individual, it is also important to consider how their condition affects their wider family. These families have to make adaptations in all aspects of life to accommodate the disabled child with it often challenging to show resilience in times of difficulty. Resilience within an ecological approach can be defined as “good outcomes in spite of serious threats to adaptation of development” with its focus mainly around interaction between the individual and their environment (Masten, 2001:228). However, moving towards a more constructionist view, Ungar (2004) regarded the ability to be resilient as dependent on access to particular resources. According to this model of resilience, material resources such as sufficient financial and employment opportunities as well as feelings of power and control over one’s life help aid resilience. For families with disabled children, the disability can have detrimental effects on the parent’s ability to work, in turn having a negative effect on financial resources. The need for power and control over their lives cannot be met due to limited power over the child’s disability. With it being difficult to meet the necessary resources among families with children with disabilities, their ability to express resilience is hindered.

Resilience among families coping with childhood disability was investigated among five hundred and thirty-eight families living in Canada (McConnell et al., 2014). The three-year study found that families with access to more resources such as social

support and less financial difficulty expressed greater resilience than those facing financial hardship and social isolation. They concluded that social resources were a strong predictor of resilience among families raising children with disabilities, therefore supporting a constructionist approach. As many of the social resources considered necessary to build up resilience are dependent on parents, much of past research has focused on parents rather than the wider family. The protective factors and resources found within families with disabled children were investigated among sixty-eight families (Greeff et al., 2012). Qualities such as family coherence were a predictor of resilience, with coherence improving with high levels of family commitment and feelings of control in stressful circumstances. Parent's ability to be involved in their work as well as support networks found among friends and wider family were also found to be predictors of resilience, further reinforcing the concept of resources helping to build resilience within families with a disabled child.

With parents potentially struggling to acquire the resources needed to be resilient towards their child's disability, this can have a knock-on effect on the wider family. Bowen's Family Systems Theory (1978) characterises the individual as being part of their wider family unit with each member having considerable influence on the entire system. Within this theory families are a multigenerational, emotionally connected unit with changes in one generation impacting on others (Klever, 2005). With regards to families coping with disability, the disabled child can have extensive effects on parental relationships as well as on sibling relations and development. Research on changes in family dynamics and structure among families with disabilities found that parents of disabled children were more likely to separate and leave the child with the mother than parents of non-disabled children (Hatton et al., 2010). There has been considerable research on the impact of child disability on parents yet far less on the wider family.

There is an increasing understanding that siblings play a crucial role in the development of personality and identity extending throughout the lifespan (Lamb, 2014). With regards to families where one sibling is disabled, the typically developing sibling may experience the perceived stigma, isolation and social barriers that are encountered by their disabled sibling, known as disability by association (Burke, 2010). Along with this they may experience different family life to that of their peers, often facing apparent neglect from their parents. As they progress through the lifespan, typically developing siblings may go on to share care duties of their elderly parents. Yet in cases where one sibling is disabled, the dynamic is often very different with the typically developing sibling finding themselves caring for their sibling as their parents become less able.

Other effects on siblings have been less documented within disability research compared to studies relating to parental impact and even more so relating directly to the impact of Dravet Syndrome. Much of the existing research has taken a more negative stance highlighting the possible adverse outcomes of having a disabled sibling. Strohm (2001) identified siblings of disabled individuals as being at risk of poor psychosocial functioning. Similarly, Williams (2009) found that parents of children with cystic fibrosis and cancer reported mainly negative effects on their other children. In a study carried out by Mulroy et al. (2008), parents to children with either Down Syndrome or Rett Syndrome were required to complete a questionnaire on the advantages and disadvantages for their non-disabled children in which key themes were generated. Positive themes included tolerance and acceptance of difference,

compassion and maturity whereas negative themes were around time constraints and the effect on their parent's emotions. Although this study assessed the advantages as well as the disadvantages of having a disabled brother or sister, it was also from the parents' perspective rather than siblings themselves as with much of the research in this area. O'Brien et al. (2009) concluded that it is essential to gain insight into the siblings own perspective in order to understand their experiences.

The online Sibling Voices Survey was designed to investigate the impact of severe childhood epilepsies on siblings and yielded one hundred and eighty-three responses across parents and three sibling age groups, with the analysis choosing to focus on the two younger sibling groups (Bailey et al., 2017). Siblings reported concerns over the possibility of their siblings' death as well as parent unhappiness. The survey was developed to improve a poorly researched area and use the knowledge obtained to develop meaningful and helpful resources for families coping with severe childhood epilepsy.

Rationale

The impact of childhood disability on the wider family has tended to focus more on the influence on parents and their ability to access external resources, with this being a strong predictor of their ability to be resilient. Within a family systems framework is the concept that each family is interconnected, with an issue experienced by one member experienced by the whole system which consequently highlights the need to investigate the direct impact disability has on siblings (Bowen, 1978).

Although past research has explored this to an extent, the majority has focused on parent's perspectives rather than siblings themselves (Mulroy et al., 2008). Those few exploring it from siblings' perspectives have shifted their focus towards younger children meaning the experience of adult siblings has been underrepresented (Bailey et al., 2017).

Therefore this study has set out to produce a thorough exploration of adult siblings' experience of growing up with a disabled sibling, focusing specifically on Dravet Syndrome. Through the perspective of siblings themselves, the main aims were to investigate whether age of diagnosis impacted siblings' experience; whether the historical understanding of Dravet Syndrome had improved over time and if so whether this enabled a more positive experience; and finally whether their experience had changed from childhood to adulthood drawing on any key themes that had emerged. Using interviews and thematic analysis within a narrative framework, an accurate and comprehensive account of the personal experience of growing up with a sibling with Dravet Syndrome has been produced.

Methodology

Philosophical Underpinnings

Epistemology is concerned with how we acquire knowledge and the understanding of what it means to know that particular knowledge (Cohen et al., 2007). The present study was within the interpretive paradigm in that it's epistemology was subjective and people established meaning to the phenomena of growing up with a sibling with a

disability in different ways (Crotty, 1998). The way meaning is constructed is relative to the positioning in their social world (Clarke and Braun, 2013).

The ontological position within this paradigm is one of relativism. Ontology relates to the origins of reality and within this paradigm is the concept that reality is subjective and differs from person to person (Scotland, 2012).

Design and Data Collection

Qualitative research was the most suitable design given that this particular research was concerned with individual experiences of a particular phenomenon and the meaning attached (Taylor et al., 2015). Interviews were an appropriate choice of data collection to allow the researcher to better understand the meaning behind their experiences (Seidman, 2013). The interviews ranged from ten to forty-one minutes and took place over the telephone. Carrying out the interviews in this way was appropriate for this particular research given that Dravet Syndrome is a rare disease and finding siblings willing to participate proved to be quite difficult. Obtaining participants from across the country, as well as two in America, it would not have been cost or time effective to conduct face to face interviews. Similar research investigating parental experiences with Dravet syndrome used semi-structured interviewing along with a questionnaire with the majority of participants completing both over the telephone (Nolan, et al. 2006).

Participants

A purposive sample of six participants was recruited through an advertisement on a closed and private Dravet Syndrome UK Facebook group (Appendix 1) after obtaining permission from one of the founders of the group (Appendix 2). Due to a lack of initial responses the advertisement was additionally posted on the Dravet Parent and Caregiver Support Facebook Group, obtaining one American participant. The small sample size was suitable for the chosen design and analysis of the study, ensuring rich detailed accounts were obtained from the interviews as well as producing thorough comprehensive analyses of the transcripts. A narrative analysis of interviews with South African mothers of disabled children also used six participants (Muthukrishna and Ebrahim, 2014). Purposive sampling was the most suitable form of sampling for this research given that Dravet Syndrome is a rare condition and so it was beneficial to use participants from a target population with particular characteristics (Etikan et al., 2016). Past research in the disability field has also used purposive sampling to recruit children suffering with Cerebral Palsy to investigate their health-related quality of life which a random sample would not have been able to generate (Young et al., 2007). The inclusion criteria was individuals over the age of eighteen with a sibling with Dravet Syndrome. Exclusion criteria included anyone under the age of eighteen and those with a sibling with a different developmental disorder.

Participant Information

Participant's ranged from eighteen to thirty-six years old with four being female and two being male. Alex was aged twenty-three at the time of interview and his brother Tom eighteen. Their brother Will with Dravet Syndrome was twenty at the time of interview and was eight when he was diagnosed. Both Alex and Tom attended boarding school during childhood and all three brothers lived separately, away from home, at the time of interview. Amy was twenty at the time of interview with her

younger brother Sam, with Dravet Syndrome, fourteen. Sam was diagnosed at age four and was her mum and step-dad's son. Amy also had another older and younger brother as well as her dad having two more children with his partner. Amy lived away at university studying Psychology at the time of interview. Emily was twenty-one at the time of interview with older brother Mark, with Dravet Syndrome, twenty-three. Mark was diagnosed when he was ten years old. Emily's parents were divorced and she lived at home with her brother and mum whilst studying Medicine at university. Kate was thirty at the time of interview and was from America. Her younger sister Lizzie, with Dravet Syndrome was twenty-four at the time of interview and was diagnosed when she was twelve. Kate lived at home with her husband, sister and mother. Sarah was thirty-six at the time of interview and younger brother Josh with Dravet Syndrome was thirty-three, and diagnosed at twenty-three. Sarah was originally from the UK but had lived in America for two years with her husband and two-year-old daughter at the time of interview.

Data Analysis

Thematic analysis was deemed the most appropriate form of analysis due to the flexible framework in which it operated (King, 2004). The flexibility allowed the study to be approached from a narrative framework as the participants reflected back to their childhood, considered how the experience affected them now as adults as well as reporting what they envisaged for the future. Semi-Structured interviews allowed participants to add more information and open up about their experience. It was essential that the chosen method of analysis also allowed for this level flexibility rather than follow a rigid approach. The analysis was applied independent of existing psychological theories and assumptions in order to approach it with an objective viewpoint and discover unique and independent findings (Guest et al., 2012). Where individual personal accounts are concerned it is imperative to consider all aspects of the data to ensure a correct interpretation of their experience. Thematic analysis allowed this to take place as thoroughly as possible due to the many different stages. Becoming accustomed with the data and searching for initial codes, followed by devising these into themes, reviewing the themes and finally naming and defining them, allowed for an exhaustive analysis delving deeper than description (Braun and Clarke, 2006). Initial codes of fear of the unknown, parental strain, escaping responsibility, neglect and personal impact were generated. This led to the final themes; "The Challenge of Dravet Syndrome" which involved the struggles they had faced as a result the condition's rarity such as misdiagnosis and incorrect medication; "Impact on Family and Daily Life" relating to differences in their childhood compared to peers and the level of responsibility that was required from them; and "Impact on Development of Self" which focused on how having a sibling with Dravet Syndrome affected how they had developed as an adult.

Ethical Considerations

The current study adhered to British Psychological Society (BPS) ethical guidelines ensuring that the BPS principles of respect, competence, responsibility and integrity underpinned the entire process. Ethical approval was obtained from Manchester Metropolitan University Psychology department prior to the study taking place (Appendix 3).

Although the study was advertised via a Facebook group, participants responded by email to ensure anonymity of those choosing to respond and participate. This meant

they were not personally approached and it was their own choice whether they responded to the advertisement. Prior to the study commencing, a participant information sheet was available, highlighting the purpose of the research before they decided if they wanted to participate (Appendix 4) For those choosing to continue, informed consent was obtained before any data collection took place with participants signing a consent form outlining the full aims and objectives of the study as well as informing them of their right to withdraw hence avoiding any deception (Appendix 5). Upon completing the study all participants were fully debriefed (Appendix 6). To further ensure participants anonymity, interviews were transcribed and all names were replaced with pseudonyms and data stored on a password protected device, which only the researcher had access to.

The interview followed a schedule (Appendix 7) and participants were invited to reflect back to potentially difficult periods during their childhood. However the interviews were handled professionally yet also empathetically to ensure the participants felt comfortable. As the interviews had the risk of bringing up sensitive memories it was important for them to be carried out in a location of their choice so they felt comfortable, which interviewing over the telephone allowed. The semi-structured nature of the interviews also allowed the participant to feel relaxed as it was more of a discussion than a formal interview, with the aim to help them feel comfortable sharing their experience. The participants were also asked to consider the positive aspects rather than draw on it being entirely negative. Also by providing the interview schedule prior to the interviews taking place, it allowed them to think about their responses and not be taken aback by any of the questions.

Throughout the study there was a risk of the researcher being too emotionally involved and appearing subjective given that they had also grown up with a sibling with Dravet Syndrome. However throughout the study the researcher handled it with uttermost professionalism and approached it objectively. Although this was a potential risk, it was also a benefit in that the researcher was able to empathise with the participants and ensured the data was handled with care.

Thematic Analysis

Theme 1: The Challenge of Dravet Syndrome

As the participants reflected back to when symptoms first emerged, it was clear that it was a time of difficulty and confusion with many of their siblings experiencing misdiagnosis or their family receiving little information about the disorder. Relating to the period of time from the first seizure up until receiving the correct diagnosis, the detrimental effects on the child and in turn on the whole family were apparent.

“He had his first seizure at just under one year of age...misdiagnosed and prescribed the wrong medication... he was very severe at the time and on life support...the medication that he was on wasn’t right for him and actually had an adverse effect on him” (Amy: Lines 13-34)

Seizures were apparent in their siblings within the first year of life yet diagnosis was a long way off. At the time there was little information regarding the severity or long-term effects of the condition as their seizures first emerged many years ago. The initial

fear only worsened as the child's seizures continued and their development regressed. The concept of quality of life and wellbeing is regarded as being able to be fulfilled if the individual feels happy, enjoys life and feels hopeful about the future (Mirowsky and Ross, 2003). For families with a remarkably ill child and very little knowledge of what the future may hold, it can often be difficult to achieve high quality of life and a sense of wellbeing.

Although the prolonged period of time waiting for a correct diagnosis was expressed as difficult, for some the diagnosis of Dravet Syndrome was worse.

“alarm bells started ringing once we realised that...it was more one of these very hard very untraceable, very little known about it type of thing.” (Tom: Lines 55-58)

After years of waiting for a correct diagnosis, in some cases having already received a misdiagnosis, eventually being told their sibling had a life limiting disorder was a whole new scenario to worry about and adapt to. The time of diagnosis was a tricky one with it generating both positive and negative effects on the wider family. On the positive side it typically meant better seizure control as the child was finally given more appropriate medication. It also enabled their families to be put into contact with those going through a similar situation, enabling them to receive the right support. However, diagnosis also brought with it negative elements, as the family learnt the severity of Dravet Syndrome as well as the possibility of them requiring full-time care for their entire life.

Although diagnosis is daunting for the entire family, the need for it to happen early is important to give families time to adjust whilst the child is young. Whereas later diagnosis brings with it different medications, potentially new doctors and more tests causing further disruption to family life. A slightly more common yet still rare condition known as Spinal Muscular Atrophy (SMA) also involves a drawn out diagnosis phase due to little information known about it among professionals. Focus groups and interviews with sixty-four parents of children with SMA found that they expressed the need for newborn screening to bring forward diagnosis (Qian et al., 2015). The study concluded how fundamental early diagnosis was, firstly for the child with the condition to prevent it from worsening and secondly for the family so they could adapt to the situation and have suitable resources in place to benefit the wider family unit.

With parents stressed about the uncertainty of their child's future, this left little focus and energy for their other children who faced difficulties and changes to their childhood compared to peers without a disabled sibling.

Theme 2. Impact on Family and Daily Life

Growing up with a disabled child in the family changes the dynamics, often affecting parent's ability to work as well as their relationship with each other, taking a toll on their marriage and testing their patience. With it often creating rifts between them, the other children in the family may hold their disabled sibling responsible and often hold feelings of resentment towards them for causing this. Sarah's dad walked out on the family, a frequent occurrence in families with children with disabilities.

“My dad always felt a lot of resentment towards Josh because he felt like he never got the son that he should have got...my dad always felt quite robbed...the divorce was just enough for him to step away from us for a long time” (Sarah: Lines 137-143)

This powerful excerpt highlighted how difficult it could be for parents to witness children go through difficulty and deviate away from norms, not developing like expected. However, rather than both parents supporting each other in what was perhaps the hardest situation they had to face, the father walked away leaving the stress and care duties to his wife and daughter. This concept of resentment towards his son reflects a linear model of disability in which there is clear emphasis between typical and atypical development. Fisher and Goodley (2007) found mothers to young disabled children opposed this model of disability, wanting to appreciate and accept their children for who they were rather than abiding by the standards and expectations set by society. It is important to move away from this linear model of disability so that there is less preconceptions around what is a normally developing child to encourage parents to not feel resentment towards their disabled children.

Families often struggle to find childcare for their disabled child especially in the early days when it is unclear what their condition is, making it difficult for ordinary child-minders to take on the role. More often than not the parent takes on the role of primary carer with their other children also taking on care duties or missing out on a typical childhood due to parents simply not having enough time to cater for their every need.

“I think we felt almost a bit neglected at times...so much of her efforts were spent on trying to make Sam better.” (Amy: Lines 97-98)

It became apparent that each individual felt as though their parents focus was shifted more towards their disabled sibling during childhood. One participant reflected on her parent's uncertainty for her brother's survival, meaning all their focus was directed on striving to make him better. For such parents, it has been recognised in legislation that they should be entitled to short break provision to give them a break from caring duties (Teather, 2011). Interviews with parents of disabled children, including parents of children with Dravet Syndrome reported their experience around short break provision (Collins et al., 2014). Parents reflected how it helped them to provide better care for their disabled and non-disabled children, however the way in which parents utilised the break differed between families. For some the respite ensured they spent time with their other children to avoid feelings of neglect, yet for others they used the time to engage in activities still related to their disabled child such as being involved in related charities.

Although as adults each participant could understand why their parents went to these lengths, they admittedly reported that as small children they could not understand why their sibling received the special treatment. It was clear across the interviews that each participant was required to make sacrifices during their childhood with many having a more dysfunctional family life compared to their peers.

“there was always an atmosphere of anxiety...it was always lovely going to friend's houses...it was nice to be out of that pressurised environment which other families don't experience.” (Sarah: Lines 223-230)

It can be seen that going to friends houses was a sense of escape from their own family and in a way they idealised their normality. Although reporting their peers as a positive escape, many reflected how there was a lack of understanding from their friends or that it was difficult to see the kind of relationship they had with their siblings. This created a sense of jealousy that they could not experience the same kind of bond. Similar results were found where young siblings compared their relationship with their disabled brother or sister to their peers and expressed feelings of sadness that they could not participate in the same activities with their sibling due to their disability (Moyson and Roeyers, 2012). This research interviewed younger siblings however in the present study the siblings reported that these feelings of sadness and jealousy were no longer there, suggesting that they grew out of these views as they got older and more mature.

It was evident that the participants grew up with a sheer amount of responsibility and pressure, almost as if taking on the role of another parent. It was clear that they did not have typical brother or sister duties and that they were required to mature and grow up at a much faster pace.

“I was the third parent.” (Sarah: Lines 276-277)

“Its literally a case of life or death because he could die in the night because you’ve not heard him.” (Sarah: Lines 129-130)

The way Sarah reflected on how she felt liable for his life was a powerful demonstration of a young child feeling an extreme level of pressure and responsibility. Many reported knowing how to administer life saving medication or knowing how to put their sibling in the recovery position, which even for some adults would have been a daunting task. It is not surprising that some felt as though they needed to escape the situation and have some time for themselves.

“when I got to the point where...I couldn’t really take anymore that’s when I made the decision to go to boarding school...almost as a break and a bit of respite for myself.”
(Tom: Lines 77-80)

The concept of needing respite as a young child indicated how difficult Tom’s childhood was. Having put his disabled brother first his whole life, it eventually reached a point where he had to think of himself. Having not done this could have caused detrimental effects on their relationship. Past research has found that positive sibling relationships have improved peer socialisation and school outcomes for the disabled child (Floyd et al., 2009). Close sibling relationships when one has an intellectual or developmental disability was a strong predictor of future caregiving by the non-disabled sibling from a survey completed by seven hundred and fifty-seven adult siblings (Burke et al., 2012). Not getting the respite he needed could have impacted Tom’s future involvement with his disabled brother. This was the case for another of the participants who grew up with a great deal of responsibility for her brother with not much choice in the matter. This led her to become very distant from him with it being clear that the level of responsibility that had been thrust upon her had pushed her away as an adult.

However, growing up with such a level of responsibility and intensity, although stressful, had an encouraging impact on characteristics the participants developed and carried into adulthood.

Theme 3. Impact on Development of Self

Although they each regarded their experience as being very difficult and overwhelming at times whilst growing up, now as adults the majority considered the experience as having an overall positive effect on their development and who they had become as a person. All believed that they would not be who they were if they had not had a disabled sibling and many believed they would take over the responsibility for them in the future.

“without him I definitely wouldn’t be doing what I’m doing now...he has grown me as a person...he has basically made me the person I am today.” (Emily: Lines 114-124)

Whilst for some being in a hospital environment for a lot of their childhood could have caused them to be very opposed to a career in the same area, for a few it actually motivated them to pursue a career in a related field. They were interested in helping people in the same way that their family had been helped and supported over the years. Similar findings were obtained by Dyke et al. (2008) showing that siblings to those with Down Syndrome and Rett Syndrome tended to opt for careers in health settings. The majority expressed how their sibling had enabled them to become extremely empathetic and organised. However, one participant expressed through her disheartening account how the experience had a huge negative impact on her and determined how her life ran its course.

“it did impact me on having my own children...I insisted on getting tested first genetically to see if I did carry the Dravet gene because if I had then I would have not had children.” (Sarah: Lines 171-174)

Sarah was the only participant to share such negative views about her experience and the only participant who was a parent. The majority of the other participants were in different stages of their life and so had perhaps not yet considered starting their own family. Existing literature has found similar worries among siblings who feared that when it came to having their own children they could have the same condition as their disabled brother or sister (Burke, 2010). For some of the younger participants who did not yet have a family of their own, they were accepting of the fact that one day responsibility for their sibling would fall to them.

“eventually Will will fall into our hands...when you are born with it and you have grown up with it its not that much of a scary idea anymore...you become sort of normalised and just sort of used to it” (Tom: Lines 171-176)

The brothers expressed how they had adapted to their situation almost as if it was now second nature and less of a daunting prospect that eventually he would be their responsibility. The difference in approaches between participants could be due to families with more children who act as a support network. For those with their only sibling having Dravet Syndrome, they did not have someone to confide in going through the same experience. For families without disabled children it is thought that more children cause a financial strain and a distant family bond. However for families

with disabled children the larger the family means distribution of caring duties and an abundance of support (Namkung et al., 2015). This helps to improve family wellbeing and cohesion among family members which in turn leads to resilience and a positive development of self.

Discussion

Findings from the analysis were in line with existing theory, with evidence of factors found within the Family Systems framework evident throughout the excerpts. There was clear indication of the individual with Dravet Syndrome affecting subsystems within the family unit that was demonstrated through the father leaving the family in some cases, producing similar results to existing literature (Hatton et al., 2010). For the two brothers who both attended boarding school, this displays a constructionist approach to resilience. Their ability to attend boarding school as well as their parent's financial ability to make this happen demonstrates access to material resources. Feelings of power and control could be attributed to their decision to move to boarding school to regain control over their life. These two particular resources were witnessed in other participants with one moving away to university and another moving to America. This could be seen as an escape from reality as a means to improve their resilience. For the participant who had a reduced level of power and control over her own life due to helping to care for her brother, this could explain how she was perceived as less resilient as the other participants with it hugely affecting how she developed as an adult.

It emerged that the majority of the participants at the time of interview had accepted their siblings condition and were aware of what would be required of them as they got older. The Cognitive Adaptation Model suggests that adaptation to adverse circumstances is a result of finding meaning, gaining mastery and enhancing the self with regards to the experience (Taylor, 1983). Searching for meaning through the use of Attribution Theory allows a better positive understanding of the condition. The sense of acceptance shown by all participants demonstrates how they could have come to regard their experience as positive. Gaining mastery relates to regaining control over a threatening event such as their sibling being diagnosed with a life limiting condition in which the future is unknown. By immersing themselves in relevant knowledge from seizure types to different medication, they had more of a sense of control. Enhancing the self can be witnessed in the participants through their ability to adopt a positive mentality about the future and use their experience to help support others, utilising the skills and characteristics they had developed as a result of their experience.

Past literature has found adverse effects on non-disabled siblings' psychosocial functioning (Strohm, 2001). The present study did not encounter these findings which could be attributed to self report through interviewing siblings directly. Most other research reaching these conclusions relied on parent's reports.

Limitations and Future Research

Limitations of the study included the variation of interview length with the shortest being only ten minutes. The interview was still included however it failed to provide as much detailed information as the other interviews. As one participant was from America, her experience differed to other participants with regards to professional

knowledge and access to medical resources. Future research could use participants from the same country to produce a better comparative of their experience.

Another limitation was that the researcher had a sibling with Dravet Syndrome themselves and so by immersing themselves within this particular phenomenon, sensitive and challenging memories from their own experience could have been brought up.

Summary

Although the siblings faced long periods of difficulty and extreme responsibility, it was refreshing to see that for the most part they were still active members in their disabled siblings' lives. Through their experience they had developed into resilient and remarkable individuals who still continued to support their family and mostly would eventually take on the responsibility of their sibling with Dravet Syndrome.

The findings highlighted the importance of early diagnosis and the potential detrimental effects a drawn out diagnosis can have on the entire family. There has been an improvement in professional understanding, support mechanisms and diagnostic testing of Dravet Syndrome since these participant's siblings were children, benefitting newer families in the Dravet Syndrome community. Families of children with other rare disorders could learn from these findings to understand sibling impact in the early stages.

Reflexive Analysis

Having grown up with a sibling with Dravet Syndrome myself, I was really passionate about a topic that I felt inadequately covered in existing literature. It was important to give these siblings the opportunity to reflect on their experience, that had most likely not been presented to them before. I was able to relate with the participants which I feel really enabled them to feel comfortable talking about their experience. It was interesting to see how each participant's journey differed yet I was still able to draw a lot of similarities with my own personal experience. It was heartening to see that others had also gone through a similar journey and could take from it positive outcomes.

References

- Bailey, L.D., Gammaiton, A.R., Galer, B.S., Schwartz, L. and Schad, C. (2017) '*Interim Findings from the Siblings Voices Survey: Impact of Severe Childhood Epilepsy on Siblings 17 Years of Age or Under.*' Washington: Department of Rehabilitation Medicine. [Online] [Accessed on 25th October] Available from: <http://www.w.zogenix.com/pdf/51950%20NORD%20Poster%202017-09-28v2.pdf>
- Bowen, M. (1978) *Family Therapy in Clinical Practice*. London: Jason Aronson.
- Braun, V. and Clarke, V. (2006) 'Using Thematic Analysis in Psychology.' *Qualitative Research in Psychology*, 3(2) pp. 77-101.
- Burke, M.M., Taylor, J.L., Urbano, R. and Hodapp, R.M. (2012) 'Predictors of Future Caregiving by Adult Siblings of individuals with Intellectual and Developmental Disabilities.' *American Journal on Intellectual and Developmental Disabilities*, 117(1) pp. 33-47.
- Burke, P. (2010) 'Brothers and Sisters of Disabled Children: The Experience of Disability by Association.' *British Journal of Social Work*, 40(6) pp. 1681-1699.
- Clarke, V. and Braun, V. (2013) *Successful Qualitative Research: A Practical Guide for Beginners*. London: Sage.
- Cohen, L., Manion, L. and Morrison, K. (2007) *Research Methods in Education*. 6th ed., London: Routledge.
- Collins, M., Langer, S., Welch, V., Wells, E., Hatton, C., Robertson, J. and Emerson, E. (2014) 'A Break from Caring for a Disabled Child: Parent Perceptions of the Uses and Benefits of Short Break Provision in England.' *The British Journal of Social Work*, 44(5) pp. 1180-1196.
- Crotty, M. (1989) *The Foundations of Social Research*. London: Sage.
- Dominguez, N. (2017) *What is Dravet Syndrome?* Dravet Syndrome Foundation. [Online] [Accessed on 25th October 2017] <https://www.dravetfoundation.org/what-is-dravet-syndrome/>
- Dravet, C. (2011) 'Dravet Syndrome History.' *Developmental Medicine and Child Neurology*, 53(s2) pp. 1-6.
- Dyke, P., Mulroy, S. and Leonard, H. (2008) 'Siblings of Children with Disabilities: Challenges and Opportunities.' *Acta Paediatrica*, 98, pp. 23-24. [issue number missing]
- Etikan, I., Musa, S.A. and Alkassim, R.S. (2016) 'Comparison of Convenience Sampling and Purposive Sampling.' *American Journal of Theoretical and Applied Statistics*, 5(1) pp. 1-4.

Fisher, P. and Goodley, D. (2007) 'The Linear Medical Model of Disability: Mothers of Disabled Babies Resist with Counter-Narratives.' *Sociology of Health and Illness*, 29(1) pp. 66-81.

Floyd, F.J., Purcell, S.E., Richardson, S.S. and Kupersmidt, J.B. (2009) 'Sibling Relationship Quality and Social Functioning of Children and Adolescents with Intellectual Disability.' *American Journal on Intellectual and Developmental Disabilities*, 114(2) pp. 110-127.

Greeff, A.P., Vansteenwegen, A. and Gillard, J. (2012) 'Resilience in Families Living with a Child with a Physical Disability.' *Rehabilitation Nursing*, 37(3) pp. 97-104.

Guest, G., MacQueen, K.M. and Namey, E.E. (2012) *Applied Thematic Analysis*. London: Sage.

Hatton, C., Emerson, E., Graham, H., Blacher, J. and Llewellyn, G. (2010) 'Changes in Family Composition and Marital Status in Families with a Young Child with Cognitive Delay.' *Journal of Applied Research in Intellectual Disabilities*, 23(1) pp. 14-26.

King, N. (2004). 'Using Templates in the Thematic Analysis of Text.' In Cassell, C. and Symon, G. (ed.) *Essential Guide to Qualitative Methods in Organizational Research*. London: Sage, pp. 256–270.

Klever, P. (2005) 'The Multigenerational Transmission of Family Unit Functioning.' *The American Journal of Family Therapy*, 33(3) pp. 253-264.

Lamb, M.E. (2014) 'Sibling Relationships Across the Lifespan: An Overview and Introduction.' In Lamb, M.E. and Sutton-Smith, B. (ed.) *Sibling Relationships: Their Nature and Significance Across the Lifespan*. New York: Psychology Press, pp. 1-11.

Masten, A. S. (2001) 'Ordinary Magic: Resilience Processes in Development.' *American Psychologist*, 56(3) p. 227-238.

McConnell, D., Savage, A. and Breitzkreuz, R. (2014) 'Resilience in Families Raising Children with Disabilities and Behaviour Problems.' *Research in Developmental Disabilities*, 35(4) pp. 833-848.

Mirowsky, J. and Ross, C.E. (2003) *Social Causes of Psychological Distress*. Chicago: Aldine Press.

Moyson, T. and Roeyers, H. (2012) "'The Overall Quality of My Life as a Sibling is All Right, But of Course, it Could Always Be Better'. Quality of Life in Siblings of Children with Intellectual Disability: The Siblings' Perspectives.' *Journal of Intellectual Disability Research*, 56(1) pp. 87-101.

Mulroy S., Robertson, L., Aiberti, K., Leonard, H. and Bower, C. (2008) 'The Impact of Having a Sibling with an Intellectual Disability: Parental Perspectives in Two Disorders.' *Journal of Intellectual Disability Research*, 52(3) pp. 216-229.

Muthukrishna, N. and Ebrahim, H. (2014) 'Motherhood and the

Disabled Child in Contexts of Early Education and Care.' *Childhood*, 21(3) pp. 369-384.

Namkung, E.H., Song, J., Greenberg, J.S., Mailick, M.R. and Floyd, F.J. (2015) 'The Relative Risk of Divorce in Parents of Children with Developmental Disabilities: Impacts of Lifelong Parenting.' *American Journal on Intellectual and Developmental Disabilities*, 120(6) pp. 514-526.

Nolan, K. J., Camfield, C. S. and Camfield, P. R. (2006). 'Coping with Dravet Syndrome: Parental Experiences with A Catastrophic Epilepsy.' *Developmental Medicine and Child Neurology*, 48(9) pp. 761-765.

O'Brien, I., Duffy, A. and Nicholl, H. (2009) 'Impact of Childhood Chronic Illnesses On Siblings: A Literature Review.' *British Journal of Nursing*, 18(22) pp. 1358-1365.

Qian, Y., McGraw, S., Henne, J., Jarecki, J., Hobby, K. and Yeh, W.S. (2015) 'Understanding the Experiences and Needs of Individuals with Spinal Muscular Atrophy and Their Parents: A Qualitative Study.' *BMC Neurology*, 15(1) pp. 1-12.

Scotland, J. (2012) 'Exploring the Philosophical Underpinnings of Research: Relating Ontology and Epistemology to the Methodology and Methods of the Scientific, Interpretive, and Critical Research Paradigms.' *English Language Teaching*, 5(9) pp. 9-16.

Seidman, I. (2013) *Interviewing as Qualitative Research: A Guide for Researchers in Education and the Social Sciences*. 4th ed., New York: Teachers College Press.

Strohm, K. (2001) 'Sibling Project: A Project in South Australia is Pioneering the Provision of Services for Siblings of Children with Disabilities or Chronic Illness--A Group Whose Needs Are Only Beginning to be Recognised in Australia.' *Youth Studies Australia*, 20(4) pp. 48-53.

Taylor, S.E. (1983) 'Adjustment to Threatening Events: A Theory of Cognitive Adaptation.' *American Psychologist*, 38(11) pp. 1161-1173.

Taylor, S.J., Bogdan, R. and DeVault, M. (2015) *Introduction to Qualitative Research Methods: A Guidebook and Resource*. 4th ed., New York: John Wiley and Sons.

Teather, S. (2011) *Children and Young Persons England: The Breaks for Carers of Disabled Children Regulations*. London: Department for Education. [Online] [Accessed on 20th March 2018] Available from: http://www.legislation.gov.uk/ukxi/2011/707/pdfs/ukxi_20110707_en.pdf

Ungar, M. (2004) 'A Constructionist Discourse on Resilience: Multiple Contexts, Multiple Realities Among At-Risk Children and Youth.' *Youth and Society*, 35(3) pp. 341-365.

Williams, P.D., Ridder, E.L., Setter, R.K., Liebergen, A., Curry, H., Piamjariyakul, U. and Williams, A.R. (2009). 'Pediatric Chronic Illness (Cancer, Cystic Fibrosis) Effects

on Well Siblings: Parents' Voices.' *Issues in Comprehensive Pediatric Nursing*, 32(3), 94–113.

Wu, Y.W., Sullivan, J., McDaniel, S.S., Meisler, M.H., Walsh, E.M., Li, S.X. and Kuzniewicz, M.W. (2015). 'Incidence of Dravet Syndrome in a US Population.' *Pediatrics*, 136(5) pp. 1310-1315.

Young, B., Rice, H., Dixon-Woods, M., Colver, A.F. and Parkinson, K.N. (2007) 'A Qualitative Study of the Health-Related Quality of Life of Disabled Children.' *Developmental Medicine and Child Neurology*, 49(9) pp. 660-665